

ADD UPDATE

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Message From the Commissioner

As we welcome 2011, I want to take a moment to wish all of you a healthy and happy New Year, and to both reflect on the past year and look toward the future.

The past few years have been incredibly challenging, with economic difficulties touching all Americans and forcing hard choices in every state in the country. People with disabilities are particularly affected by a long list of complex issues -- changes in Medicaid and Medicare, rising poverty rates, the new economic reality of States, persistent unemployment, education reform efforts, and the growing aging population -- these concerns are only a small sample of the shifting landscape.

At the same time, we have seen tremendous successes that will greatly benefit people with disabilities, including the passage of the Affordable Care Act, Rosa's Law, the Twenty-First Century Communications and Video

Accessibility Act, and a renewed national focus on employment of people with disabilities.

Times of great change and great difficulty also create great opportunities. ADD is looking to all of you, as a community of people who care deeply and passionately about Americans with intellectual and developmental disabilities, to harness these opportunities and help us create the future we envision.

To that end, as many of you know, ADD has been holding a series of regional listening summits in cities across the country (for more information, see page 15), and will host a national stakeholders meeting in Washington DC in late January. The regional summits, held in Philadelphia, Orlando, Dallas, Detroit, and Denver, gave us an opportunity to hear from hundreds of individuals who came from 44 states to participate in person. We listened to your

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success stories, heard about your dreams, empathized with your struggles, recorded your concerns, and gathered your ideas. To those of you who participated, a tremendous thank you. Your input, your experiences, your solutions—all of these are absolutely essential as ADD looks forward and begins to create a five-year plan—a blueprint for our future. Summaries from the summits are available at www.envision2010.net, and a draft strategic plan will be posted online this spring for public commentary.

We hope that this strategic plan will be a continuing leg on the long journey of creating the future we imagine...

A future where all children with disabilities are able to live healthy lives in loving homes with their families, have real friends and full social lives, and achieve academic success in inclusive schools.

A future where adults with intellectual and developmental disabilities are employed in integrated workplaces and earning a competitive wage, living in homes and communities of their choosing, and achieving economic self-sufficiency.

A future where aging parents do not have to fear for the quality of the lives of their sons and daughters with disabilities, and can live out the last years of their lives in peace, knowing that their family members will have others to help support and care for them.

A future where all people, including people who have been labeled as “significantly,” “severely,” or “profoundly” disabled, are supported to exercise choice, control and self-determination to participate fully as contributing members

of our interdependent, integrated and inclusive communities.

And a future where the intent of both the DD Act and the ADA – the promise of equal opportunity, economic self-sufficiency, independent living, and full participation as well as integration and inclusion in all facets of community life – is made real and meaningful for all people with intellectual and developmental disabilities.

To work towards anything less would be a loss to all of us, as a country, as a society. Our sons and daughters, brothers and sisters, and colleagues and friends with disabilities have so much to offer our communities and our country as citizens, employees, volunteers, and contributors. We need to hold on to our high expectations and our big dreams.

As ADD’s Commissioner, I am absolutely committed to making our schools, communities, workplaces, and neighborhoods more welcoming and inclusive for individuals with intellectual and developmental disabilities. I believe strongly in supporting approaches that shape attitudes by raising expectations, that change outdated or broken systems, that engender respect for all people, and that empower individuals with disabilities to pursue the lives they envision for themselves.

The challenges before us are substantial, but so are our imaginations, our commitment, and our abilities. I look forward to working together as we define and shape a better future for all people with disabilities.

My sincere best wishes to you and your families for the New Year.

As ADD’s Commissioner, I am absolutely committed to making our schools, communities, workplaces, and neighborhoods more welcoming and inclusive for individuals with intellectual and developmental disabilities.



Department of Justice Publishes New ADA Regulations

As part of the Administration's commemoration of the twentieth anniversary of the Americans with Disabilities Act in July 2010, the Department of Justice (DoJ) published final regulations for Titles II and III of the Americans With Disabilities Act (ADA), including ADA Standards for Accessible Design.

The revised rules amend regulations under Title II, which applies to public entities, and Title III, which applies to public accommodations (businesses that are generally open to the public and fall within one of twelve categories established by the statute, such as restaurants, movie

theaters, schools, day care facilities, recreational facilities and doctors' offices). Additionally, DoJ announced preliminary rulemaking processes to modernize the ADA regulations to address the accessibility of equipment and furniture, websites, movies shown in theaters, and 911 services. The 2010 standards, which can be used immediately as an alternative to the current standards, become mandatory March 15, 2012. A full explanation of these changes, and a full listing of the 2010 Standards for Accessible Design, are available at www.ada.gov/2010ADASTandards_index.htm.

SUMMARY OF CHANGES

(adapted from Department of Justice Fact Sheets available at <http://www.ada.gov/regs2010/ADAregs2010.htm>)

1. Adoption of the 2010 ADA Standards for Accessible Design. The Department has adopted revised ADA design standards that include the relevant chapters of the Access Board's 2004 ADA/ABA Accessibility Guidelines as modified by specific provisions of this rule. To minimize compliance burdens on entities subject to more than one legal standard, these design standards have been harmonized with the Federal standards implementing the Architectural Barriers Act and with the private sector model codes that are adopted by most

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States.

2. Effective Date. The rule will become effective on March 15, 2011. On March 15, 2012, compliance with the 2010 Standards will be required for new construction and alterations. In the period between September 15, 2010 and March 15, 2012, covered entities may choose between the 1991 Standards, the Uniform Federal Accessibility Standards (UFAS), and the 2010 Standards. Covered entities that should have complied with the 1991 Standards or the UFAS during any new construction or alteration of facilities or elements, but have not done so by March 15, 2012, must comply with the 2010 Standards.

3. Element by Element Safe Harbor. The rule includes a general "safe harbor" under which elements in covered facilities that were built or altered in compliance with the 1991 Standards or the UFAS would not be required to be brought into compliance with the 2010 Standards until the elements were subject to a planned alteration. Similar safe harbors were adopted for elements associated with the "path of travel" to an altered area.

4. Ticketing. The rule provides guidance on the sale of tickets for accessible seating, the sale of season tickets, the hold and release of accessible seating to persons other than those who need accessible seating, ticket pricing, prevention of the fraudulent purchase of accessible seating, and the ability to purchase multiple tickets when buying accessible seating. It requires a venue operator to accommodate an individual with a disability who acquired inaccessible seating on the secondary ticket market only when there is unsold accessible seating for that event.

5. Service Animals. The rule defines "service animal" as a dog that has been individually trained to do work or perform tasks for the benefit of an individual with a disability. The rule states that other animals, whether wild or domestic, do not qualify as service animals. Dogs that are not trained to perform tasks that mitigate the effects of a disability, including dogs that are used purely for emotional support, are not service animals. The final rule also clarifies that individuals with mental disabilities who use service animals that are trained to perform a specific task are protected by the ADA. The rule permits the use of trained miniature horses as alternatives to dogs, subject to certain limitations. To allow flexibility in situations where using a horse would not be appropriate, the final rule does not include miniature horses in the definition of "service animal."

6. Wheelchairs and Other Power-Driven Mobility Devices. The rule adopts a two-tiered approach to mobility devices, drawing distinctions between wheelchairs and "other power-driven mobility devices." "Other power-driven mobility devices" include a range of devices not designed for individuals with mobility impairments, such as the Segway® PT, but which are often used by individuals with disabilities as their mobility device of choice. Wheelchairs (and other devices designed for use by people with mobility impairments) must be permitted in all areas open to pedestrian use. "Other power-driven mobility devices" must be per-

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mitted to be used unless the covered entity can demonstrate that such use would fundamentally alter its programs, services, or activities, create a direct threat, or create a safety hazard. The rule also lists factors to consider in making this determination. This approach accommodates both the legitimate business interests in the safe operation of a facility and the growing use of the Segway® PT as a mobility device by returning veterans and others who are using the Segway® PT as their mobility aid of choice.

7. Effective Communication. The rule includes video remote interpreting (VRI) services as a kind of auxiliary aid that may be used to provide effective communication. VRI is an interpreting service that uses video conference technology over dedicated lines or wireless technology offering a high-speed, wide-bandwidth video connection that delivers high-quality video images. To ensure that VRI is effective, the Department has established performance standards for VRI and requires training for users of the technology and other involved individuals so that they may quickly and efficiently set up and operate the VRI system.

8. Residential Housing Offered for Sale to Individual Owners. Residential housing programs provided by title II entities are covered by the ADA. For the first time, however, the final rule establishes design requirements for residential dwelling units built by or on behalf of public entities with the intent that the finished units will be sold to individual owners. These design requirements are set forth in the 2010 Standards.

Detention and Correctional Facilities. The final rule clarifies the requirements that apply to correctional facilities. It requires three percent of newly constructed or altered cells to be accessible.

Reservations Made by Places of Lodging. The rule establishes requirements for reservations made by places of lodging, including procedures that will allow individuals with disabilities to make reservations for accessible guest rooms during the same hours and in the same manner as other guests, and requirements that will require places of lodging to identify and describe accessible features of a guest room, to hold back the accessible guest rooms for people with disabilities until all other guest rooms of that type have been rented, and to ensure that a reserved accessible guest room is removed from all reservations systems so that it is not inadvertently released to someone other than the person who reserved the accessible room. The final rule limits the obligations of third-party reservation operators that do not themselves own and operate places of lodging. In addition, to allow the hospitality industry appropriate time to change reservation systems, the final rule gives places of lodging 18 months from the publication date, September 15, 2010, to come into compliance with these requirements.

11. Timeshares, Condominium Hotels, and Other Places of Lodging. The rule provides that timeshare and condominium properties that operate like hotels are subject to title III, providing guidance about the factors that must be present for a facility that is not an inn, motel, or hotel to qualify as a place of lodging. The final rule limits obligations for units that are not owned or substantially controlled by the public accommodation that operates the place of lodging. Such units are not subject to reservation requirements relating to the "holding back" of accessible units. They are also not subject to barrier removal and alterations requirements if the physical features of the guest room interiors are controlled by their individual owners rather than by a third party operator.

Affordable Care Act Rollout Explained

(content adapted from HHS website healthcare.gov)

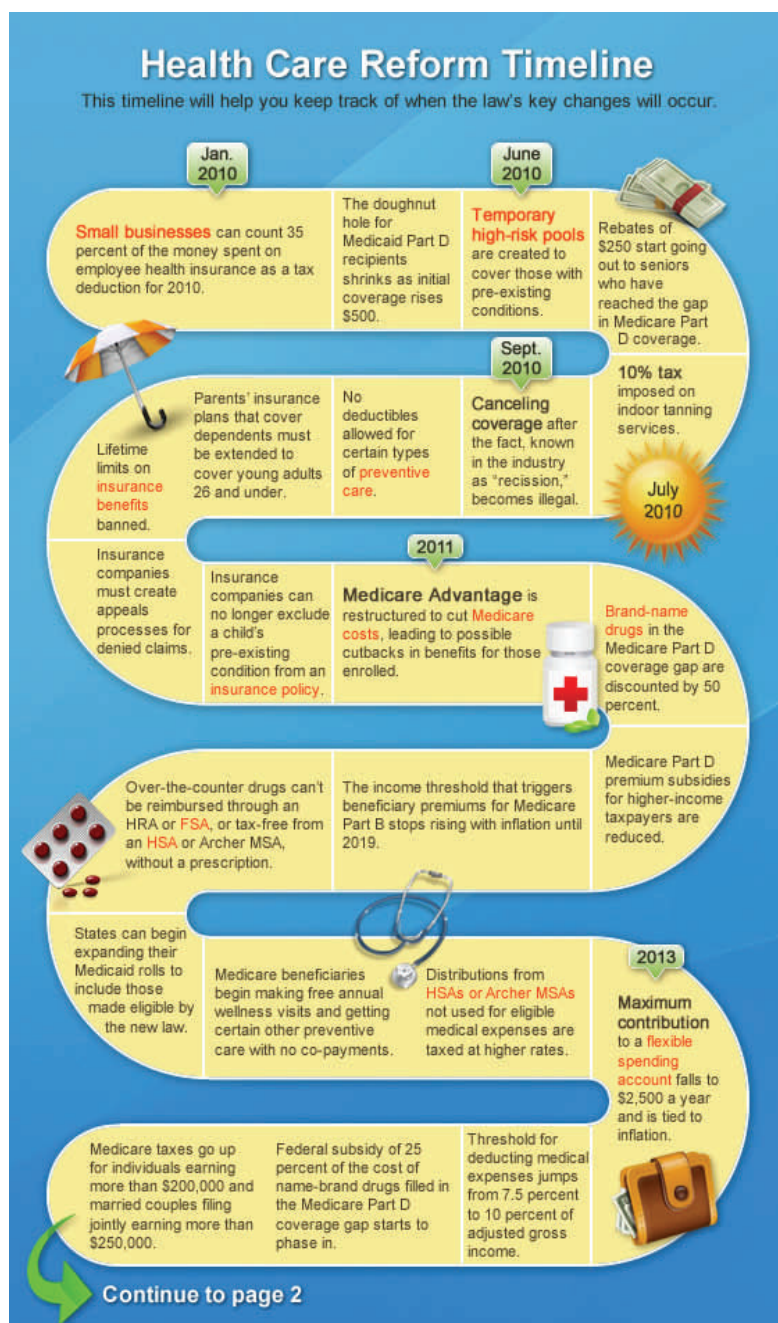


Image courtesy of bankrate.com

New health care reforms under the Affordable Care Act will have a significant impact on the lives of all Americans.

These reforms will give Americans new rights and benefits, including helping more children get health coverage, ending lifetime and most annual limits on care, and giving patients access to recommended without cost-sharing. These reforms will apply to all new health plans, and to many existing health plans as they are renewed. Many other new benefits of the law have already taken effect, and more rights, protections and benefits for Americans are on the way now through 2014.

Knowing your rights and getting regular preventative care are some of the most important things you can do to take charge of your health.

To help people keep track of health care changes, the U.S. Department of Health and Human Services has launched a new website, www.healthcare.gov/index.html.

It will be regularly updated, and should serve as your go-to site for information about your rights and how the Affordable Care Act will affect you.

From HealthCare.Gov: Top Five Things to Know for People With a Disability

1. If you're living with a disability, private health insurance may be hard to come by. Even if

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you can afford to buy it, it probably doesn't cover all of your needs. Worrying about where to get coverage and the cost of your care is the last thing you want to do. The Affordable Care Act is expanding your options for health insurance and making them more affordable.

2. Effective now, job-based and new individual plans won't be allowed to deny or exclude coverage to any child under age 19 based on a pre-existing condition, including a disability. Starting in 2014, these same plans won't be able to exclude anyone from coverage or charge a higher premium for a pre-existing condition including a disability.
3. Effective now, insurance companies won't be able to drop you if you get sick just because you made a mistake on your coverage application.
4. Effective now, insurance companies can't include lifetime limits on your coverage.

Medicaid covers many people with disabilities now, and in the future it will provide insurance to even more Americans. Starting in 2014, most adults under age 65 with incomes up to about \$15,000 per year for single individual (higher income for couples/families with children) will qualify for Medicaid in every state. State Medicaid programs will also be able to offer additional services to help those who need long-term care at home and in the community.

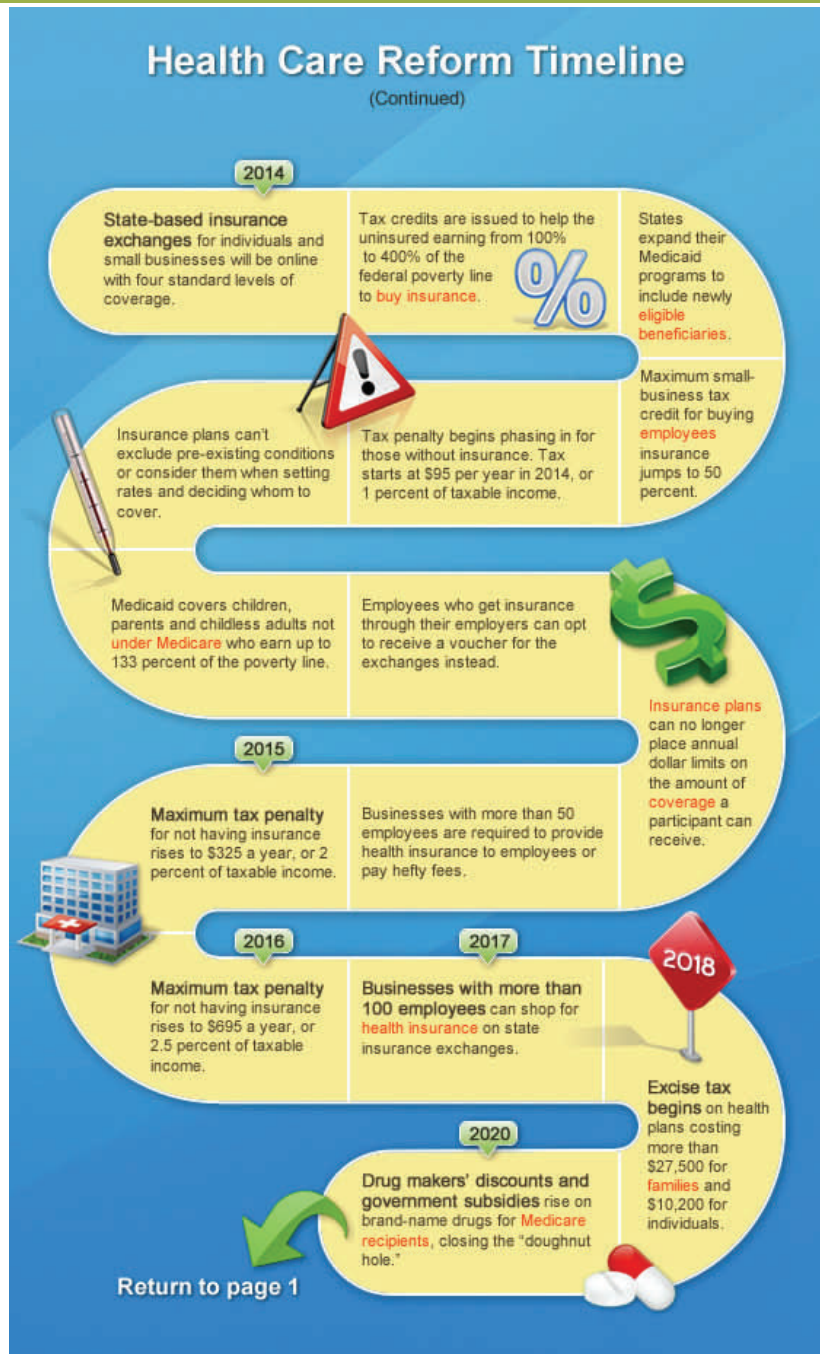


Image courtesy of bankrate.com

5. You may be able to join and get benefits from a voluntary, enrollment-based insurance program that will be available after October 2012 called the Community Living Assistance Services and Supports (CLASS) Program. It will provide assistance to people who need help with daily activities. Under this voluntary program, you'll get a cash allowance so you can get care and other supports to help you keep your independence.



AP PHOTO

President Barack Obama hugs nine-year-old Rosa Marcellino after signing the law named in her honor.

President Obama Signs Rosa's Law

What you call people is how you treat them. If we change the words, maybe it will be the start of a new attitude towards people with disabilities .

-Nick Marcellino

On October 5, 2010, President Barack Obama signed Rosa's Law ([S. 2781](#)), replacing the term 'mental retardation' in several Federal laws with 'intellectual disability.' The bill does not change or restrict opportunities available to individuals with intellectual disabilities; it simply makes the Federal law language consistent with that used by the Centers for Disease Control, the World Health Organization, and the White House.

ADD Commissioner Sharon Lewis remarked on the passing of Rosa's law, saying, "Language matters – our words have incredible power, influencing how we treat people. Rosa's Law acknowledges a fundamental shift in our nation's respect for, and value of, people with intellectual and developmental disabilities as our friends, our peers, our colleagues, and our family members. It is wonderful to see this bill become law, driven by the grassroots efforts of self-advocates and families."

Rosa's Law echoes a similar law recently adopted in the state of Maryland. It was inspired by nine-year-old Rosa Marcellino, a Maryland resident who has Down syndrome. When Rosa was in kindergarten, her mother Nina learned that she had been labeled with the "R Word" at school. Nina didn't allow that word in her house, and her other children

didn't think of Rosa that way. Rosa's family worked with their state representative to pass legislation in Maryland that changed the terminology used to refer to individuals with disabilities. During that process, Nina met Maryland Senator Barbara Mikulski. The Senator promised Nina that if the law was passed in Maryland, she'd take it to the Senate floor.

"The Marcellinos' story is a perfect example of effective citizen advocacy. They pulled together to pull us all to another way of thinking. They fought for the respect and dignity of a loved one. The more than 6 million people with intellectual disabilities in America deserve that same respect and dignity," Senator Mikulski said.

On the occasion of signing Rosa's Law, president Obama said, "As one of hundreds of thousands of Americans with Down syndrome, Rosa worked with her parents and her siblings to have the words "mentally retarded" officially removed from the health and education code in her home state of Maryland. Now, Rosa's Law takes her idea a step further. It amends the language in all Federal health, education and labor laws to remove that same phrase and instead refer to Americans living with an "intellectual disability." Now this may seem to some people like a minor change, but I think

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Rosa's brother Nick put it best.....He said, *What you call people is how you treat them. If we change the words, maybe it will be the start of a new attitude towards people with disabilities.* That's a lot of wisdom from Nick."

It is indeed a lot of wisdom, and Nick is only fifteen years old.

There has been a great deal of discussion about the "R Word" in recent years, and ADD

applauds the efforts that states, grantees, organizations, and individuals have made to remove the word from the national vocabulary. Because as Nick said, what we call people is how we treat them. Words are ideas, and ideas change the world. Sometimes the most powerful ideas are the simplest- the idea that Rosa is as entitled as her brother and sisters to respect and dignity at school and in her daily life. The idea that the experience of one family can result in the changed laws of a nation. The idea that we have the ability to refuse to accept the world the way it is, and through that refusal, change it.

Spotlight on Self-Advocates

There has been much emphasis lately on the issue of language. With the passage of Rosa's Law and the national spotlight on bullying (see pages 8 and 11 of this issue of the ADD Update), individuals, communities, and lawmakers have been talking about the labels we use and the impact of words on our society. People with intellectual and developmental disabilities have long been the leaders of this conversation. They have been at the forefront of the movement to eliminate the use of the "R-Word," and they have been key players in the advancement of a multitude of human and civil rights.

Victor Robinson is just one of many self-advocates working to promote a variety of causes that improve the lives of individuals with disabilities. For the past eight years, Mr. Robinson, a DC resident, has been a member of Self-Advocates Becoming Empowered (SABE), most recently serving as the SABE board's treasurer. He has also worked for the past three years as a Community Outreach Specialist at the Quality Trust for Individuals with Disabilities, an organization whose mission is to be an

independent catalyst for change in the lives of people of all ages with developmental disabilities in the District of Columbia.



In his personal and professional life, Mr. Robinson is dedicated to educating individuals with disabilities about their rights, and to championing the causes most important to him—among them, elimination of the "R-Word," employment for individuals with disabilities, and violence against women with disabilities.

"When I talk to self-advocates, I think the most important thing is knowing about their rights," says Mr. Robinson. "Some of them don't know about their rights at all. Some people may be misinformed. They may have some information, but not all of it."

"A person just wants to have a life of their own,"

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he says. “They say, I want to be free. They just want to live out there and do things like everyone else. They want to live a life just as if they didn’t have a disability.”

Mr. Robinson’s goal is to help them do just that.

Over the past eight years, much of his work with SABLE has involved a state-by-state effort to remove the “R-Word” from state law language. He has participated in marches, given speeches, and met with governors and mayors.

“A person was always offended by that,” says Mr. Robinson, of the prevalence of the use of the “R-Word” in both state law and day-to-day conversation. “They never wanted to be called that. Nobody-- disabled or non-disabled-- wants to be called names.”

“People who are disabled shouldn’t be labeled,” he says. “They shouldn’t be discriminated against. People should always be respected, and not looked at in a different way. If a person is trying just to have a normal life, that shouldn’t be commented on. Everyone can achieve things.”

One crucial step toward a “normal life” is employment, says Mr. Robinson. More than almost anything else, he believes, employment leads to self-sufficiency, freedom, and independence.

The most important message, he says, is to “have respect, have equality. A lot of people want to work out there, they just need encouragement.”

Through his community outreach, Mr. Robinson works to provide that encouragement. He teaches people how to network, and what sources to use when looking for a job. “Look in newspapers,” he says. “Ask a friend. If you want to find a job

or look for a life of your own, you have to search for it.”

Mr. Robinson is also dedicated to preventing violence against individuals with disabilities, particularly women. The importance of this issue was highlighted for him by the future Mrs. Robinson, Thelma Green.

Mr. Robinson and Ms. Green met almost 17 years ago, and he proposed in April. “When she’s upset about things, I’m the one to cool her down,” says Mr. Robinson. “When she was sad, I was always the one to cheer her up. Her mother thanked me for being the one to bring her out of her shell. She didn’t used to want to go out, I was the one who could draw her

out. We respect each other, we love each other very much.”

Like her future husband, Ms. Green is an activist. One of her passions is protecting women with disabilities against violence, and she has drafted Mr. Robinson to the cause.

“Learning self-defense and how to protect yourself is important for women with disabilities,” says Mr. Robinson. My fiancée is passionate about that. A lot of people who are disabled are victims of crime, and they don’t let anyone know about it. She’s trying to speak out, and so am I. We want our friends to know about these things.”

Mr. Robinson and Ms. Green look forward to a life together—to working to speak up about the issues that are important to them both, to supporting each other, to a shared house and a shared future.

“We can’t wait to live together,” says Mr. Robinson. “We just want to have a normal life. To not have any trouble. We respect each other. Whenever there’s trouble between us, we work it out. If there’s conflict in my family or her family, we sit down and talk about it and work it out. We always want to be a little soft on each other. We always want to trust each other. We have an equal relationship.”

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People should always be respected,
and not looked at in a different way.

Dealing with Bullying

Over the course of the past year, bullying has become a topic of national controversy and conversation.

On January 14, 2010, the suicide of Massachusetts teenager Phoebe Prince led to the criminal prosecution of six teenagers, to the enactment of stricter anti-bullying legislation by the Massachusetts state legislature, and to a nationwide discussion about bullying. The deaths by suicide this summer and fall of several teens and young adults after bullying related to their sexual orientation further prompted a national outcry.

Bullying leads to a host of concerns, including school absences, depression, anxiety and psychological issues, poor academic performance, low self-esteem, and—as evidenced by the recent tragedies—thoughts of suicide.

While bullying in all its forms is certainly not a problem unique to individuals with disabilities, bullies often single out as their victims anyone who is deemed “different,” and students with disabilities frequently experience a higher rate of bullying than their non-disabled peers. One of the simplest ways we as a community can address the problem of bullying is to educate students about differences of all kind and promote inclusion, not just of people with disabilities, but of all people. We can, and must, do more as communities to combat bullying, empower students to protect themselves, and promote acceptance of diversity.

In the modern age, bullying is no longer relegated to the cafeteria and playground. It extends to the ever-expanding and hard-to-regulate terrain of cyberspace. According to the National Crime Prevention Center, 40 percent of all teens with access to the internet have reported being bullied online. While schoolyard bullying is difficult to deal with, cyber-bullying can up the ante. It is often harder for parents and educators to regulate, and increases cruelty under the cloak of anonymity.

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BULLYING BY THE NUMBERS

(adapted from bullyinginfo.org; for references and more federal data, see www.findyouthinfo.gov/topic_bullying_widespread.shtml)

- Bullying peaks in middle childhood, and decreases over the high school years (Finkelhor, Turner, Ormrod, Hamby, & Kracke, 2009; Goldbaum, Craig, Pepler, & Connolly, 2003; Nansel et al., 2001).
- Studies show that between 15 to 25 percent of U.S. students are bullied with some frequency (“sometimes or more often”) while 15 to 20 percent report that they bully others with some frequency (Melton et al., 1998; Nansel et al., 2001). Rates of bullying are higher among younger students; almost 43 percent of 6th graders report having been bullied, compared to about 24 percent of 12th graders (U.S. Department of Justice, 2007).
- In a 2009 nationally-representative sample of youth grades 9-12, 19.9% reported being bullied on school property in the 12 months preceding the survey. The prevalence was higher among females (21.2%) than males (18.7%) (Eaton et al., 2010).
- In 2007, about 32% of students aged 12 to 18 reported being bullied at school during the school year. The most common types of bullying at school included

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Bullying is a problem nationwide, and there has been a nationwide response— by parents, by students, by communities and educators, and by the Federal government.

President Obama, in a taped message that was part of the “It Gets Better Project,” a campaign aimed at reassuring bullied gay and lesbian youth that things *do* get better, said, “Like all of you, I was shocked and saddened by the deaths of several young people who were bullied and taunted for being gay, and who ultimately took their own lives. As a parent of two daughters, it breaks my heart. It’s something that just shouldn’t happen in this country. We’ve got to dispel the myth that bullying is just a normal rite of passage – that it’s some inevitable part of growing up. It’s not. We have an obligation to ensure that our schools are safe for all of our kids. And to every young person out there you need to know that if you’re in trouble, there are caring adults who can help... As a nation we’re founded on the belief that all of us are equal and each of us deserves the freedom to pursue our own version of happiness; to make the most of our talents; to speak our minds; to not fit in; most of all, to be true to ourselves. That’s the freedom that enriches all of us. That’s what America is all about. And every day, it gets better.”

In early 2010, the Obama Administration launched the Federal Partners in Bullying Prevention Steering Committee, a interagency initiative between the U.S. Departments of Education, Health and Human Services (HHS), Agriculture, the Interior, and Justice (for full membership, see: http://www.findyouthinfo.org/spotlight_FBIBPSC.shtml).

On August 11-12, 2010, the Steering Committee sponsored the first-ever National Bullying Summit. The summit brought together over 100 participants— top representatives from Federal, state, and local government agencies; researchers; corporate leaders; and students. Secretary of Education Arne Duncan gave the opening remarks, saying, “The fact is that no school can be a great school until it is a safe school first. A positive school climate is foundational to start academic achievement.”

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being made fun of, being the subject of rumors, and being pushed, shoved, tripped, or spit on. Only about a third of victims notified a teacher or another adult about it (Dinkes, Kemp, & Baum, 2009).

- Among children and youth aged 17 and younger, about 1 in 5 report being physically bullied, and about 3 in 10 report being teased or emotionally bullied in their lifetime. Among children aged 10 to 17, about 8% report having been the victim of Internet harassment (Finkelhor et al., 2009).
- Bullying is experienced by both boys and girls. While boys experience more physical and verbal bullying, girls experience more psychological/relational bullying (Finkelhor et al., 2009; Wang, Iannotti, & Nansel, 2009).
- Research indicates that children with disabilities or special needs are at a higher risk of being bullied than other children (Rigby, 2002).
- Gay, lesbian, and bisexual youth are more likely to report being bullied than are heterosexual youth (Berlan et al., 2010).

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Over the course of the summit, attendees took part in panels, attended presentations, and participated in break-out groups to discuss the underlying causes of bullying and develop a national strategy to end it.

During 2010, the Bullying Prevention Steering Committee also reported its engagement in the following activities:

- Inventorying federal efforts, activities, and resources for bullying;
- Identifying gaps and needs;
- Consulting with outside experts;
- Designing new programmatic initiatives to address gaps and needs

In addition, the committee launched the website bullyinginfo.org a one-stop website that brings all federal resources on bullying to one place for the first time ever.

Another Federal initiative to combat bullying is the Stop Bullying Now! Campaign, launched by the U.S. Department of Health and Human Services' Health Resources and Services Administration. The campaign is specifically targeted to the youth and teens who are at the heart of the bullying debate. It aims to combat bullying by reaching youth directly, and by raising awareness among the families, educators, and communities who care about them. The website includes resources for adults and tips, games, webisodes and videos for students.

<http://www.stopbullyingnow.hrsa.gov/kids/>

The Department of Education was also at the center of the Federal bullying efforts. In October, the Department issued guidance to support educators in combating bullying in schools by emphasizing how and when student bullying may violate federal education anti-discrimination laws. The guidance is available

here: <http://www2.ed.gov/about/offices/list/ocr/letters/colleague-201010.html>. The Department of Education plans to hold a series of technical assistance workshops around the country to help educators end bullying in their schools.

In addition to the general bullying initiatives, resources exist that are geared specifically toward students with disabilities and their families.

The PACER National Center for Bullying Prevention is one group dedicated to raising awareness and increasing understanding of how to respond to bullying, especially as it relates to K-12 students with disabilities. Founded in 1977, the PACER Center was created by parents of children and youth with disabilities to help other parents and families facing similar challenges.

Today, PACER Center works to expand opportunities and enhance the quality of life of children and young adults with disabilities and their families. The Center for Bullying Prevention is just one component of its work. The Center promotes awareness, provides a forum for individuals to share their experiences, and shares resources for parents, schools, and students. Its offerings include fact sheets on bullying statistics, classroom activities that focus on preventing and combating bullying, guidelines for influencing decision-makers, and tips for creating change.

For more information, see <http://www.pacer.org/bullying>.

ADD grantees and stakeholders who are participating in anti-bullying efforts should contact Rebekah Yeager at rebekah.yeager@acf.hhs.gov to share their findings, best practice information, and outcomes.

ADD and Project Search

Washington DC high school senior Justine Thomas spent the last three months interning at ADD.

Justine was here as part of Project SEARCH, a school-to-work transition and training program for students with disabilities in their last year of high school. The program takes place at a host business where students benefit from both workplace immersion and classroom instruction. The program is designed to increase in employability skills, career exploration, and training through worksite rotations. Students attend the program for a full academic year beginning late August and ending mid-June. During this time, students participate in three 10-12 week rotational traineeships. The goal of the Project SEARCH is to increase job skills, build confidence, and ease the transition process as students graduate, leading to competitive employment opportunities and fulfilling careers.

This year, the Federal government incorporated a Project SEARCH program into offices at the Department of Health and Human Services, the Department of Education, and the Department of Labor. Over the course of the full school year, Justine and her fellow students will have the opportunity to experience a variety of government offices, to build relationships with Federal employees, to discover their individual strengths and interests, and to build skills that will position them to be competitive in a tight job market.

"The potential is great that Justine and the other students become employed," says Justine's job coach Carolyn Price. "That's really the goal here, that they become so job-ready that they gain Federal employment. Additionally, in the course of their project placements, they will have built the relationships that will help them succeed."

"Justine was just delightful to have around. She was well-liked and appreciated and became part of the team."

-ADD Program Specialist Gina Barbaro

Because each student has three internship rotations, they have three opportunities to master needed skills, says Price. Skill sets that aren't mastered in the first rotation are focused on in the second rotation, and any additional needs can be met in the third rotation.

Says ADD Commissioner Sharon Lewis, "Supporting Justine as a Project Search student at ADD the last few months was a wonderful learning experience, both for ADD staff and for Justine. The growth we saw in Justine in a short period of time was incredible, and she made many meaningful contributions to ADD over the course of her internship."

On a typical school day, Justine started her morning at an onsite classroom located at the Administration for Children and Families. After signing in, she was responsible for specific tasks in the classroom, and then she received classroom instruction focusing on both academic and career-readiness goals. When she arrived in ADD's offices, she assisted staff in a wide range of areas. Her favorite task, she says, was scanning, part of a major undertaking to electronically archive ADD's files which greatly benefited from Justine's hard work. Other responsibilities greeting and escorting visitors, managing supply inventory, and providing clerical support to staff.

Justine's ADD supervisor, Gina Barbaro, says, "Justine was just delightful to have around. She was well-liked and appreciated and became part of the team. She was so enthusiastic about coming here to help out, and she sought out work to do."

ADD: Envisioning the Future



Participants at the Detroit Listening Summit

For the past several months, ADD has been conducting regional listening summits in order to hear how stakeholders – individuals with disabilities, family members, allies, and professionals—envision the future for people with developmental disabilities.

While there are currently many difficult issues to overcome, thanks to many years of hard work by advocates, families, and communities, the realities for people with developmental disabilities have positively evolved in recent decades. ADD formulated the listening summits as a way to gather community input on what issues we should prioritize, and what steps we should take to ensure that the future brings new opportunities and a better reality for individuals with disabilities.

Held in Philadelphia, Detroit, Dallas, Orlando, and Denver, the listening summits provided Commissioner Sharon Lewis and the ADD staff with opportunities to connect with stakeholders across the country and to learn from their experiences, concerns, needs, and ideas. The information from the summits will be used to shape ADD's five-year plan.

The public was invited to participate in a variety of ways, allowing ADD to identify emerging

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On Day One of each listening summit, presenters gave testimony across variety of topics, or life stages. For each life stage, presenters were asked to respond to a question.

Childhood (0-21):

How do we ensure that each child with a developmental disability will live a healthy and happy life in a loving family home; fully participate in all of the experiences of childhood in inclusive, welcoming communities; be empowered to advocate for themselves; and successfully graduate from school prepared for college or a career of their choosing?

Adulthood (21-60):

In the future, what will be the most important contributing factors to ensuring that adults with developmental disabilities achieve equality of opportunity, independent living, economic self-sufficiency and full participation as valued members of inclusive, integrated communities? Which critical issues must be prioritized - access to healthcare, employment, supports and services, technology, housing, transportation, other issues?

Aging (60-end of life):

Aging concerns affect us all. The number of adults with developmental disabilities age 60 years and older is projected to nearly double from 642,000 (2000) to 1.2 million (2030). What can we do to empower older individuals with developmental disabilities to remain in their own homes with a high quality of life, to maintain independence and good health for as long as possible, and to enjoy community and family relationships through the end of life?

Supports from families, caregivers, professionals and other allies:

Over 75% of people with I/DD live with families, often with aging parents. Direct support workers usually earn very low wages. Families and caregivers often struggle to access any level of formal support at all. How can we address the future caregiving and support challenges of communities, families, and the allies who care about people with developmental disabilities?

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trends in issues and concerns. Hundreds of participants submitted comments and written testimony electronically, while others shared their stories in personal testimony at the summits.

Each listening summit was a public event, and took place over the course of two days. Commissioner Lewis attended all five summits, and ADD staff members were present at each summit as well.

Participants were asked to think about the big picture -- including trends, research, and the context of broader public policy concerns.

The first day of each summit was a "listening session," and provided people with an opportunity to submit testimony. Testimonies were structured around four topics, or stages of life: childhood, adulthood, aging, and supports.

Members of the public providing testimony were asked to respond to a question related to the life stage about which they were speaking (see sidebar). The general public was invited to attend and listen. In addition, at each summit an expert panel of federal representatives and state leaders (including Commissioner Lewis) had the opportunity to ask each presenter questions after their testimony, and to speak with them regarding ideas and solutions related to the topics on which they spoke.

On the second day of the summit, stakeholders participated in a day-long "prioritization session," at which they were asked to help ADD synthesize what was heard in day one,

and to begin to identify priorities and formulate strategies. Day Two attendees were divided into small groups; each group was a cross section of self-advocates, family members, professionals, and other stakeholders. Each group worked on a related but distinct topic.

Group discussions included increasing access for people with intellectual and developmental disabilities to full participation in communities, to employment, to healthcare, to education, and to economic self-sufficiency.

Participants also addressed changes to the DD Act, which is overdue for authorization. Participants examined both improvements to implementation of the current law and suggestions for reauthorization, including issues such as accountability and reporting from the DD Network entities, research and data needs, collaboration and coordination across the DD Network, engagement of state DD staff, support for self-advocacy and family support, and direct support workforce issues.

ADD is currently working to synthesize the information gathered at the summits, and is beginning to formulate a five-year plan that reflects the experiences, needs, and ideas of the participants. National stakeholders will meet in late January to provide additional input.

The plan will be available online in the Spring at <http://www.envision2010.net/> for public comment. We welcome and encourage your input, and look forward to working with you to create the future that we, as a community, envision.

Changes to ADD's Organizational Structure

As we begin a new year, ADD is pleased to announce changes in our organizational structure that we believe will increase our capacity to serve our community.

We are also welcoming two new team members, Jamie Kendall, our new Deputy Commissioner, and Adam Gower, a participant in the Social Security Administration Advanced Leadership Program who will be on detail with ADD for several months.

In addition, we have been taking a critical look at how to maximize our staff resources to best meet the needs of individuals with disabilities and their families as well as our grantees, stakeholders,

and constituents. After much thought and analysis, we have restructured our office and staff assignments.

"We believe that way we are now organizing our work will provide better customer service, improved team approaches and will provide a greater capacity for our ADD team to work across programs," says Commissioner Sharon Lewis.

The ADD organizational structure now includes three components: the Office of the Commissioner, the Office of Program Support, and the Office of Innovation. The Office of the Commissioner will continue to provide executive leadership and

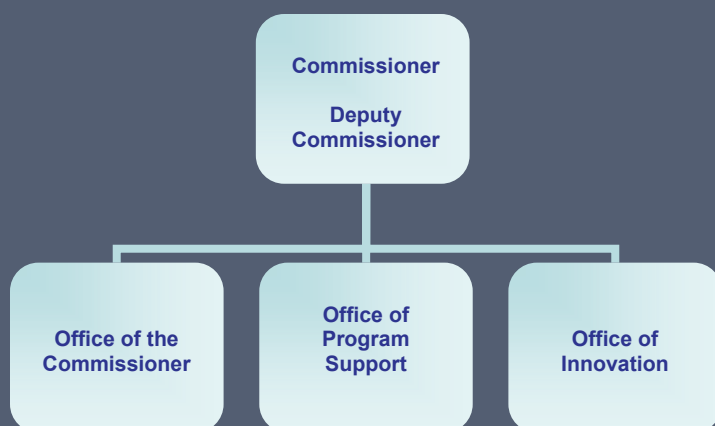
management strategies for all components of the Administration on Developmental Disabilities, and serve as the principal advisor on matters related to individuals with developmental disabilities to the Assistant Secretary for Children and Families, the Secretary, and other elements of the Department of Health and Human Services.

The Office of Program Support now provides coordination, oversight, management and evaluation of the State Councils on Developmental Disabilities, the Protection and Advocacy Systems, the University Centers for Excellence in Developmental Disabilities, and their related technical assistance contracts.

Finally, the Office of Innovation is responsible for the coordination, oversight, management and evaluation of the Projects of National Significance and grants under the Help America Vote Act, as well as communication and data management.

While we understand that the full transition will be a process, we believe that this new structure will better position us to fulfill our mission: to assure that individuals with developmental disabilities and their families participate in the design of, and have access to, needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life.

ADD's New Organizational Structure



ADD Awards New PNS Grants

In September 2010, ADD awarded 12 new grants for Projects of National Significance (PNS).

The new grants fall under four project types that concentrate on areas of emerging needs for individuals with intellectual and developmental disabilities, and they are specifically designed to be in sync with ADD's goals of sustainability and systems change. By concentrating on changing systems that aren't working, shifting paradigms, and empowering individuals with disabilities and their families, ADD believes that these PNS projects will help to ensure that individuals with intellectual and developmental disabilities can fully contribute to, and participate in, all facets of community life.

National Autism Resource and Information Center (one grant)

In September of 2010 ADD awarded The Arc of the United States \$1.87 million for fiscal year 2010 to establish a National Resource and Information Center on Autism Spectrum Disorder (ASD) and other developmental disabilities. The AutismNOW Project is collaborating with several partners, including the Autistic Self Advocacy Network, the Autism Society of America and several ADD Network entities to engage and leverage a national network of disability, aging, and family organizations.

"We are proud to have the opportunity to launch the Center," says Center co-director Tonia Ferguson. "It's a much needed resource, especially because families don't currently have one central location where they can go to get a variety of reliable information. And what I'm most excited about is that self-advocates will have a meaningful role in developing and implementing this innovative project."

The Center will provide high-quality resources and information related to community-based services that support independent living and self-determination, treatment protocols that promote community-based experiences (e.g. education, employment, recreation, transportation, early intervention and child care), and evidence-based interventions. The intended audience for the Center includes people with ASD, family members, service providers, researchers, and the general public. The Center will also host a parent-to-parent call-in center for families addressing issues relating to autism and other developmental disabilities. More information about the Center can be found at <http://www.autismNOW.org>

Family Support and Community Access Demonstration Projects (five grants)

Five Family Support and Community Access Demonstration projects have been awarded to innovative family support demonstration projects that rely on collaborative efforts and community-based solutions to reach unserved and underserved families, and to encourage systemic change and improved community capacity to support families of individuals with developmental disabilities.

"The new family support projects include a rigorous evaluation component," says ADD Project Officer Ophelia McLain, "and they focus on sustainability and systems change."

To that end, each project includes a meticulous and structured evaluation plan to demonstrate that the stated outcomes have been achieved. Grantees will be planning during the first year, and will create a sustainability plan, including the establishment of sustainability benchmarks that must be achieved by the end of year three in order to receive continued funding in years four and five.

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The grants were awarded to: The Family Support Access Expansion Center (Hampton University); Families Accessing Communities Together (The PACER Center); Michigan Family Support Initiative (Wayne State University); Supporting Families in Real Communities (Georgia Council on Developmental Disabilities); and The Families RISE (Realization, Inclusion, Self-determination, Empowerment) Project (Respite Center of San Antonio Inc).

Emergency Preparedness Special Initiatives (five grants)

“Historically, there has been a lack of inclusion of persons with disabilities in the process of preparing for an emergency situation,” says ADD Project Officer Larissa Crossen. “More than just that, there has been a lack of including people with disabilities in the training and preparation of emergency responders.”

To address this lack of inclusion, ADD awarded five implementation grants to plan multiagency partnerships to design emergency preparedness planning projects to assist unserved and underserved families with a member who has a disability. The applicants were asked to pool resources, coordinate services, and share expenses in order to effectively train individuals with developmental disabilities and family members to prepare for emergency situations. Grantees will focus on a variety of initiatives to ensure that that individuals with disabilities are engaged at all stages and aspects of emergency planning. Their focus will include methods for safe evacuation and reunification with families, continuous access to medical and mental health care, provision of accessible transportation services, provision of training to agencies responsible for emergency response activities, and other initiatives to keep individuals with

disabilities safe in the event of an emergency situation.

The grants were awarded to: Alianza Emergency Preparedness Project Plus (Cerebral Palsy Association of Middlesex County, Inc.); Being Prepared: MN Emergency Preparedness Center (IIPSI, Inc.); Collaboration for Inclusive Emergency Preparedness and Response (University of Delaware Center for Disability Studies); Hawaii Emergency Preparedness Special Initiatives (University of Hawaii-Manoa Center for Disability Studies); and PREPARation for Emergencies and Recovery (PREP) Project (University of North Carolina at Chapel Hill, Office of Sponsored Research)

Voting Project (one grant)

Because residents of the Commonwealth of the Northern Mariana Islands (CNMI) were not permitted to vote in Federal elections until 2008, they were not included under previous Federal regulations that provided assistance in making voting places accessible to persons with disabilities.

“There was a need to afford individuals with developmental disabilities on CNMI with the same access as everyone else,” says McLain.

This award will allow the Commonwealth Elections Commission in the Commonwealth of the Northern Mariana Islands to ensure that individuals with disabilities have improved information and access to polling places to vote in the areas on Saipan, Northern Islands, Rota and Tinian through training and technical assistance, and monitoring of accessibility.

For additional information and full project abstracts, please see <http://www.acf.hhs.gov/programs/add/pns/pns.html>



ADD Welcomes a New Deputy Commissioner

"I look forward to working to advance the mission of ADD and improve the lives of people with developmental disabilities."

-Jamie Kendall

In December, ADD welcomed new Deputy Commissioner Jamie Kendall. Jamie hit the ground running; her first day on the job began with a trip to Denver to participate in ADD's final Envisioning the Future Listening Summit. In the weeks that followed, Jamie quickly became an integral part of the ADD team. She comes on board at a time of transition, as ADD has just restructured its office makeup and staff assignments in order to streamline our work process and better serve the public (see page 17). ADD is pleased to start the new year with a reorganized office and a new Deputy Commissioner, and we look forward to working with her in the year to come.

"Jamie brings a wealth of public policy experience, both inside and outside of government, as well as tremendous management and leadership skills," said Commissioner Sharon Lewis. "We are very fortunate to have her join the ADD team."

Jamie comes most recently from the at the Office of Retirement and Disability Policy (ORDP), Office of Program Development and Research (OPDR), at the Social Security Administration (SSA) where she has been for the last seven years. In this capacity she was involved with the creation and management of multi million dollar demonstration projects at Social Security that focus on return to work activities for persons with disabilities. She led the efforts for the Youth Transition Demonstration (YTD), a project geared towards assisting youth on SSI in becoming self-sufficient through employment, as well as the Benefit Offset National Demonstration (BOND) project, which will institute a benefit

offset for income from employment in the SSDI program. Prior to SSA, she worked at NISH, as a Project Manager for the Ticket to Work Program. Finally, Jamie was at ACF from 1996 – 2001 in the Office of Program, Research and Evaluation, and started her federal career as a PMF working in our Atlanta regional office, the Office of the Assistant Secretary, and at the House Ways and Means Human Resources Subcommittee. Jamie holds a Masters in Public Policy (MPP) from Georgetown University.

While Jamie will work across ADD's programs and areas of focus, she has throughout her career been drawn to the issue of employment, and she looks especially forward to working on the issue of employment for individuals with intellectual and developmental disabilities.

"In my work in and out of government, I've focused on employment, which is a special interest of mine," she says. "I think it would be fair to say that employment is fundamentally important in regards to income, but working is so much more than that. Employment offers people the ability to make a contribution to something bigger than themselves, the chance to make social connections, and the opportunity to do something meaningful. Both ACF and Social Security have been involved in research related to employment, and I think research is really important, so that we can constantly strive to implement programs meaningful to the community."

"I look forward to working to advance the mission of ADD and improve the lives of people with developmental disabilities," she says.